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**Not asking cancer patients about their preferences does make a difference.
A cross-sectional study examining cancer patients' preferred and perceived
role in decision making regarding their last important cancer treatment**

ABSTRACT

Objectives: We examined whether not having been asked by their clinicians about how involved cancer patients would like to be in their treatment decisions is related to discordance between patients' preferred and perceived involvement in treatment decision making.

Methods: A cross-sectional survey of adult cancer patients recruited from five medical and radiation oncology outpatient clinics in Australia. Discordance of patients' preferred and perceived decision making roles was assessed via an adapted version of the Control Preferences Scale. Logistic regression modelling was conducted to assess the relationship between role discordance and whether patients were not asked but wanted to be asked about how involved they would like to be in deciding on their treatment.

Results: Of 423 study participants, almost a third (n=128, 31%) reported discordance between their preferred and perceived involvement in their treatment decisions. Of those reporting discordance, 72% (n=92) were less involved than they would have liked to have been. Not being asked about their preferences for involvement in treatment decisions, despite wanting this, was associated with discordance between patients' preferred and perceived involvement in treatment decision making ($p < 0.04$).

Conclusion: To achieve patient-centred care, it is vital that clinicians seek patients' views about how involved they would like to be in deciding on their cancer treatment.

Key words: cancer care; decision making; patient-centred care; doctor-patient-communication

1. Introduction

1.1 Patient-centred decision making is a cornerstone of optimal cancer care

Patient-centred healthcare is respectful and responsive to patients' needs and preferences (Richards, Coulter, & Wicks, 2015). For this to occur, patients must comprehend their disease and treatment options, consider their own preferences, participate in decision making to the degree they desire and make a decision consistent with their preferences (Mead & Bower, 2000). Providing patient-centred decision making may increase patients' understanding of their treatment options, improve their satisfaction with their decision and the consultation, and decrease decisional conflict (R. Brown et al., 2012; Hack, Degner, Watson, & Sinha, 2006).

1.2 Patient-centred decision making is not always delivered to cancer patients

Despite the importance of involving patients in treatment decisions to the extent they desire, numerous studies suggest that some clinicians do not adequately involve patients in decisions regarding their cancer treatment (Carey et al., 2012; El Turabi, Abel, Roland, & Lyratzopoulos, 2013; Seror et al., 2013). For example, Tariman and colleagues performed a systematic literature review to examine the concordance between cancer patients' preferred and perceived decision making roles (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). All 22 studies showed disagreements between patients' decision making preferences and experiences (Tariman et al., 2010). Most found that patients wanted more involvement in decision making than what they felt occurred (Tariman et al., 2010).

1.3 Effective communication is essential to delivering patient-centred decision making

Patients' preferences for involvement in treatment decisions can vary considerably by patient and disease-related characteristics, such as age, gender or stage of cancer (R. Say, Murtagh, & Thomson, 2006; Singh et al., 2010). They can also change over time, for example when situational factors change, such as patients' disease status (Butow, Maclean, Dunn, Tattersall,

& Boyer, 1997). Inadequate patient involvement can be due to clinicians' misperceptions of patients' preferences for decision making (Willems, De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005). For example, there is evidence to suggest that clinicians may not always understand when and how patients would like to receive information on their available treatment options (Coulter, Peto, & Doll, 1994). They may also overestimate patients' comprehension of information and underestimate their preferred level of involvement in treatment decisions (Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley, 2001; Denis, Joniau, Bossi, Baskin-Bey, & Fitzpatrick, 2012). As such, it is important that healthcare providers understand patients' preferences for information provision and involvement in decision making (Zucca, Sanson-Fisher, Waller, Carey, & Boadle, 2017). Although there are evidence-based guidelines available which recommend that clinicians elicit patients' preferences for how to make treatment decisions, clinicians do not always ask patients about their decision making preferences (Zikmund-Fisher et al., 2010; Zucca et al., 2017).

1.4 Research on patient involvement in decision making has been limited

A considerable number of studies have looked at whether patients' preferences for involvement in decision making match their experiences (Tariman et al., 2010; Vogel, Helmes, & Hasenburg, 2008). Also, numerous studies have suggested that in order to provide patient-centred decision making in cancer care, healthcare providers should ask patients about their preferences for involvement in decision making regarding their care (Lee et al., 2012; Zucca et al., 2017). However, to our knowledge, no study has assessed whether asking patients about their decision making preferences is associated with discordance between patients' preferred and perceived involvement in deciding on their cancer treatment. Without having such information, we cannot confidently conclude that being asked about their preferences has an impact on patients' care experiences. This study aims to help fill this gap.

Examining the importance of asking patients about their decision making preferences can help provide adequate recommendations for clinical practice and improve communication skills training for clinicians.

1.5 Aims of this study

To examine whether patients who are not asked by their healthcare providers about their desire for involvement in treatment decisions, experience discordance between preferred and perceived involvement in their last important treatment decision.

2. Methods

2.1 Design

A cross-sectional study assessing decision making preferences and experiences in outpatients attending five medical or radiation oncology units within three local health districts in New South Wales, Australia. The data included in this paper reflects one module of a larger study.

2.2 Inclusion criteria

Patients were eligible for this study if they: (i) were aged 18 years or older; (ii) were judged by clinic staff as able to read and write in English, and physically capable of taking part in this study; (iii) had been diagnosed with cancer (any type); and (iv) were attending at least their second outpatient appointment in the last six months at one of the participating treatment centres. The latter criteria was to ensure that patients could report on at least one recent oncology consultation.

2.3 Ethics approval

This study was approved by the Hunter New England Human Research Ethics Committee (approval number: 15/04/15/4.04).

2.4 Recruitment

A trained research support person or a clinic staff member provided patients with information about the research and gained patients' informed written consent to participate. The age and sex of eligible non-consenters were recorded, with the patients' permission to assess for consent bias.

2.5 Data collection

Eligible consenting patients were asked to complete a paper and pencil survey while waiting for their oncology appointment. The full survey took approximately 15-20 minutes to complete. Participants were also provided with a reply-paid envelope, to allow them to complete and return their survey to the researchers at a later date if they wished. A reminder letter was mailed to non-responding consenting patients after a period of two weeks. A second reminder letter was sent after a further two weeks of non-response.

2.6 Outcome measures

Discordance of patients' preferred and perceived decision making role was assessed via an adapted version of the Control Preferences Scale, as used in previous studies (Tariman et al., 2010). In relation to their last important treatment decision, patients were asked to indicate 1) how involved they were and 2) how involved they would like to be in making this decision. For the first question patients were asked to select one of the following response options: i) *"I made the decision about which treatment I would receive"*; ii) *"I made the final decision about my treatment after seriously considering my doctor's opinion"*; iii) *"Both my doctor and I shared responsibility for deciding which treatment was best for me"*; iv) *"My doctor made the final decision about which treatment would be used, but seriously considered my opinions"*; v) *"I left all decisions regarding my treatment to my doctor"*. When being asked about their preferred involvement in decision making, patients were encouraged to select one of the following response options: i) *"I prefer to make the decision about which treatment I*

will receive”; ii) *“I prefer to make the final decision about my treatment after seriously considering my doctor’s opinion”*; iii) *“I prefer that my doctor and I share responsibility for deciding which treatment is best for me”*; iv) *“I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinions”*; v) *“I prefer to leave all decisions regarding my treatment to my doctor”*. The first two response options of each question were categorised as “active” treatment decision making. “Sharing responsibility for the treatment decision” was considered as “collaborative” decision making; while the last two response options were classified as “passive” decision making. The Control Preferences Scale has been used extensively in cancer populations and has evidence of reliability and validity (Degner, Sloan, & Venkatesh, 1997; Singh et al., 2010).

Experiences with being asked about involvement in decision making

Patients answered the following author-derived question: “Did a doctor, nurse or other healthcare provider ask you how involved you would like to be in making decisions about your cancer care?” The following response options were used: i) *“Yes, and I wanted this”*, ii) *“Yes, but I did not want this”*, iii) *“No, but I wanted this”*, iv) *“No, but I did not want this”*, v) *“Not applicable”*. This question was informed by a review of the literature and discussions among the research team and clinical experts.

For the analysis, the response options were divided into the following categories: Being asked vs. not being asked although patients wanted this vs. not being asked but patients did not want this. This work was informed by the principles of patient-centred care which suggest that care should align with patients’ preferences. As such, we looked specifically at the patient subgroup who indicated that their care did not meet their wishes (i.e. patients who wanted to be asked but were not asked), in order to examine whether this might be associated with discordance between their preferences for and experiences with involvement in their treatment decisions. Nine patients (2.5%) indicated that they were asked, but did not want to

be asked, about their preferred level of involvement in treatment decision making. Of these, three patients (0.8%) reported discordance between their preferred and perceived level of involvement in their last important treatment decision. As the number of patients in this subgroup was too small to allow for meaningful regression analysis, this group of patients was combined with those patients who indicated that they were asked and wanted to be asked about their preferred involvement in making decisions regarding their cancer treatment.

Independent measures

The following self-reported details were also collected from the survey and used in this study: date of birth, sex, home postcode, education, cancer type, time since diagnosis, stage of cancer at diagnosis.

2.7 Statistical analysis

All analyses were conducted in Stata 14.2. Consent bias for age and sex was assessed using Chi-square tests. We used Chi-square tests to assess whether patient characteristics were associated with being or not being asked about their preferences for involvement in treatment decisions. Frequencies and percentages of patients' preferences and experiences with treatment decision making were calculated. Incomprehensible or blank survey responses were treated as missing. Weighted kappa statistics with user-defined weights was used to assess the concordance between patients' preferred and perceived role played in their last important treatment decision. We assigned "partial credit" according to how much patients' preferences and experiences differed on the five-point Control Preferences Scale: 0 for a one-point-difference, 0.25 for a two-point-difference, 0.5 for a three-point-difference and 0.75 for a four-point-difference (Cohen, 1968). This was deemed appropriate analyses as Kappa statistics have been suggested as a robust statistic useful for either interrater or intrarater reliability testing (Peters, Maathuis, Kouw, Hamming, & Hadders-Algra, 2008; Sim & Wright, 2005). Similar to our study, it has also been used to assess intra-person agreement

across preferred and actual preferences (Hitz et al., 2013). Logistic regression modelling was conducted to assess the association between discordance of patients' preferred and perceived involvement in treatment decision making and whether patients were asked and wanted to be asked about how involved they would like to be in the treatment decision making process. The outcome variable (disagreement between preferred and perceived role according to the Control Preferences Scale) was dichotomized and defined as discordance (preferred and perceived decision-making role different) vs concordance (preferred and perceived decision-making role the same). In our regression we modelled the probabilities of patients reporting discordance. The final model was adjusted for patient age and sex. We also assessed whether these characteristics were related to discordance (although this was not a primary aim of this paper). Listwise deletion was used to remove observations with missing data, so only complete data was included in the final model. The Hosmer-Lemeshow Goodness of fit test was used to assess the fit between the model and the data, with a p-value above 0.05 considered adequate. Multicollinearity was assessed; while the area under the ROC curve was evaluated to assess the final models discriminative ability, with an AUC of 0.7 or more considered acceptable.

3. Results

3.1 Participants

Seven-hundred-eighty-four eligible oncology patients were approached. Of these 527 (67%) consented to participate and 423 (54%) returned a completed questionnaire that was included in this study. Participants had a mean age of 64 years (see Table 1). More than half of the participants were female (n=234, 55%). Approximately a third of the cancer patients included in this study were receiving treatment for breast cancer (n=133, 31%) and were diagnosed more than two years ago (n=141, 34%). Fourteen patients did not answer the question about cancer type. However, as patients' cancer diagnoses were confirmed via medical records,

these patients were included in this study. Also, 21 patients reported that they had more than one type of cancer. As the exact cancer type was not known for these patients they were categorised as having an “Unknown” cancer type. There were no statistically significant differences between consenters and non-consenters with regards to age and sex ($p > 0.05$).

Table 1 – Demographic and cancer-related characteristics of study participants << *Please insert Table 1 here.* >>

3.2 Preferences for and experiences with involvement in treatment decision making

Table 2 shows patients’ preferred and perceived level of involvement in treatment decision making. Seven patients did not complete these survey items. Thus, 416 patients (98% of all study participants) were included in the analysis. One-hundred-thirty-one patients (32%) preferred an active role in making their last important treatment decision. One-hundred-sixty-two patients (39%) preferred to make the decision collaboratively with their doctor; while 123 patients (30%) preferred a passive role in decision making. Most patients ($n=288$, 69%) reported having their preferred decision making role (see Table 2). However, almost a third of participants ($n=128$, 31%) were not involved to the extent to which they would have preferred. Agreement between preferred and perceived role was moderate, with a weighted Kappa coefficient being 0.52 (95% CI: 0.44 – 0.53). Of those reporting a role discordance, 72% ($n=92$) indicated that they would have liked to be more actively involved in making their last important treatment decision than they were; whereas 28% ($n=36$) wanted a more passive role.

Table 2 – Level of agreement between preferred and perceived involvement in last important treatment decision << *Please insert Table 2 here.* >>

3.3 Association between role discordance and not being asked about preferences for involvement in treatment decisions

Of those who answered this question (n=365, 86% of all study participants), more than half (n=202, 55%) were asked how involved they would have liked to be in decision making; 81 patients (22%) were not asked, and 82 (22%) reported that this question was not applicable (Table 3). A description of patients who were and who were not asked about how involved they would like to be in decision making, including their sociodemographic and disease-related characteristics is provided in Table 3. No statistically significant associations were found between patients' sociodemographic and disease-related characteristics and whether patients were asked about their preferences for involvement in decision making.

Also, no statistically significant differences were found between patients' age and sex and patient role discordance (Table 4). However, adjusting for age and sex, we found a statistically significant association between discordance of patients' preferred and perceived involvement in their last important treatment decision and patients reporting having not been asked how involved they would like to be in treatment decision making, although they wanted this ($p < 0.04$; OR: 2.37; 95% CI: 1.07 – 5.20, Table 4). Patients who reported having not been asked how involved they would like to be in their treatment decision, although they wanted this, had significantly higher odds of experiencing discordance between their preferred and perceived involvement in their last important treatment decision, compared to those patients who reported having been asked how involved they wanted to be. The Hosmer-Lemeshow Goodness of fit statistic was 3.70 and not significant ($p = 0.88$). The area under the receiver operating characteristic (ROC) curve was 0.55. Patients who indicated that this question was not applicable to them were excluded from the analysis (n=82, 22%). However, the level of agreement between preferred and perceived involvement for those patients included in the regression analyses are reported in Table 5, and are similar to the larger sample (weighted Kappa=0.57; 95% CI: 0.53 - 0.60).

Table 3 – Characteristics of study participants who indicated whether they were asked by their healthcare provider about their preference for involvement in treatment decision making

Table 4 – Characteristics associated with discordance between preferred and perceived involvement in decision making (logistic regression)

Table 5 – Level of agreement between preferred and perceived involvement in last important treatment decision for the reduced sample included in regression analyses

4. Discussion

4.1 Asking the patient is the first step towards delivering patient-centred care

Our study results emphasise that not asking patients about their preferred involvement in cancer treatment decision making might lead to care that does not align with patients wishes. We found that almost a third of cancer patients in our study did not attain their preferred decision making role and most of these patients were less involved than they would like to be. Our data also indicates that patients who were not asked by their healthcare providers how involved they would like to be, although they wanted this, had higher odds of reporting discordance between their preferred and perceived level of involvement in their treatment decisions. In order to deliver patient-centred care, clinicians should ask patients about their decision making preferences, rather than making assumptions about what patients want, or deciding on their behalf (Weston, 2001). Clinical judgement of patients' decision making preferences does not always reflect patients' actual preferences (Denis et al., 2012; Schubart, Toran, Whitehead, Levi, & Green, 2013). It may also be inappropriate to rely on patient characteristics or stereotypes, such as age or gender, to assume what patients' preferences for involvement in treatment decision making may be (Hubbard, Kidd, & Donaghy, 2008). Eliciting patients' decision making preferences by asking them how they would like to make

treatment decisions could help provide high-quality patient-centred cancer care (Richards et al., 2015).

4.2 Why some healthcare providers may not ask their patients about their preferences for involvement in decision making

We found no associations between patients' sociodemographic and disease-related characteristics and whether patients were asked about their preferences for involvement in decision making (Table 3). These results may suggest that patients from all sub-groups are asked at a similar rate as to whether they would like to be involved in their treatment decisions or not. However, further research assessing a wide range of patient characteristics in a more representative sample is needed to explore this issue further. As suggested by previous studies, some healthcare providers have raised concerns that asking patients about their decision making preferences and tailoring care accordingly could increase clinicians' time pressure (France Légaré, Ratté, Gravel, & Graham, 2008). However, evidence is lacking as to whether more time is required to engage patients in medical decision making (Stacey, O'Connor, Graham, & Pomey, 2006; Whelan et al., 2003). Some healthcare providers may believe that their patients do not want to be asked about their decision making preferences as they do not want to take any responsibility for the treatment decision (R. E. Say & Thomson, 2003). Yet, there is considerable evidence to suggest that although not all patients wish to be involved in healthcare decision making, they would like their healthcare provider to ask them about their preferences and take their preferences into account when making treatment decisions (Coulter, 2010). It is also possible that some clinicians do not feel capable of adequately asking patients about their preferences due to a lack of skills or experience (Lugtenberg, Zegers-van Schaick, Westert, & Burgers, 2009). A direct question regarding patients' preferred involvement in decision making may not be understood by the patient

(Elwyn, Barr, et al., 2013). Clinicians may need to use various communication techniques to ascertain how involved patients wish to be.

4.3 How to help clinicians ask patients about their preferences and adequately involve them in treatment decisions

In order to provide optimal, patient-centred care, it is essential that clinicians are open to discussions around the variance in patients' preferences for decision control. It might be helpful to discuss with patients how much and what kind of information they would like to receive, and how much time they need to familiarise themselves with the risks and potential benefits of their available treatment options (General Medical Council, 2008). Such discussions could be a first step towards eliciting how engaged patients would like to be in deciding on their care. To help facilitate this, numerous training programmes on patient-centred decision making have been introduced into professional development for healthcare providers (France Légaré et al., 2012). However, training in patient-centred decision making has not yet been widely implemented into clinical practice (France Légaré et al., 2012). More research is warranted to examine which components of decision making programmes are most effective and why, in order to increase clinicians' confidence in such programmes and facilitate their implementation into routine cancer care (F. Légaré et al., 2010).

Also, training on patient-centred decision making should be provided on a continuous basis given that communication skills can decline over time (Ha & Longnecker, 2010). Ongoing formal or informal coaching on patient-centred decision making could increase clinicians' confidence in involving patients in decisions regarding their care. For example, it has been suggested that such coaching could assist clinicians and patients with using self-administered strategies designed to improve adequate patient engagement in healthcare decisions (Katz, Belkora, & Elwyn, 2014). One such strategy are decision aids which provide patients with evidence-based information on the options available to them and support patients with

choosing the option that aligns with their preferences (International Patient Decision Aid Standards Collaboration, 2005). Decision aids intend to encourage patients to communicate their preferences and participate more in the decision making process (Holmes-Rovner, 2007). Numerous studies have shown that decision aids improve a number of patient outcomes, for instance by reducing patients' decisional conflict and increasing patients' understanding of the options available to them (Stacey et al., 2014). However, the routine use of decision aids in clinical practice is not yet commonplace (Elwyn, Scholl, et al., 2013). Early evidence suggests that coaching on patient-centred decision making could help increase the use of such decision support strategies in clinical practice (Belkora et al., 2015; Volz, Moore, & Belkora, 2015).

4.4 Limitations

Recall bias may have occurred with those patients who have had a relatively long period of time between their last important treatment decision and survey completion providing incomplete or inaccurate responses. Prospective studies in this area are needed to reduce the likelihood of recall bias occurring. Also, patients' preferences for decision making may have changed over time and might have been different at the time when the decision was made compared to the time when they completed the survey for this study. Longitudinal studies might help investigate this issue. The survey did not ask patients to reflect on one specific type of treatment, rather patients were asked to reflect on their last important treatment decision. Consequently, patients may have been referring to different types of treatments and may have different preferences for treatment decision making depending on the treatment they are deciding on (R. Say et al., 2006). The final regression model had an AUC of 0.55, which suggests that its discriminative ability was poor. However, AUC thresholds are context dependent and an AUC of > 0.5 might be acceptable in this setting (Halligan, Altman, & Mallett, 2015; Hanczar et al., 2010).

Finally, this study only assessed patients' perceived involvement in their last important treatment decision. We did not assess their actual involvement, and whether clinicians actually asked patients about their preferences. Examining patients' perceived involvement in treatment decision making is important because if patients are not perceiving to receive their preferred care, patient-centred care is not being delivered to them. However, it is possible that there is a difference between patients' perceived and their actual involvement in making their last important treatment decision. Observational studies are needed to examine whether patients' perceived role matches their actual role in decision making regarding their cancer treatment. This might be done through qualitative analysis of audio- or video-recordings of the consultations during which the treatment decision was made (R. F. Brown et al., 2011).

4.5 Conclusion

Providing care that is respectful and responsive to patients' needs and preferences is a cornerstone of high-quality cancer care. Most patients in our study preferred playing an active or collaborative role when making cancer treatment decisions. While the majority of study participants received care that aligned with their preferences, there is room for improvement. Almost a third of cancer patients in our study were identified as not being involved in decision making to the extent they desired. Not being asked about involvement in treatment decisions, despite wanting this, was associated with discordance between patients' perceived and preferred level of involvement in decision making.

4.6 Practice implications

Clinicians should explore patients' preferences for how involved they would like to be in their cancer treatment decisions, and tailor care accordingly. Strategies, such as training programmes on patient-centred decision making or the use of decision aids, might improve doctor-patient-communication and help adequately involve cancer patients in their treatment decisions.

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Table 1 – Demographic and cancer-related characteristics of study participants

Characteristic	Respondents n=423 (%)^a
Age in years mean (SD)	64 (12)
Sex	
<i>Male</i>	189 (45)
<i>Female</i>	234 (55)
Education	
<i>High school or below</i>	237 (58)
<i>Trade or vocational training</i>	115 (28)
<i>University degree</i>	50 (12)
<i>Other</i>	6 (1.5)
Treatment centre	
<i>Treatment Centre A</i>	84 (20)
<i>Treatment Centre B</i>	105 (25)
<i>Treatment Centre C</i>	117 (28)
<i>Treatment Centre D</i>	82 (19)
<i>Treatment Centre E</i>	35 (8.2)
Cancer type	
<i>Breast cancer</i>	133 (31)
<i>Colon cancer</i>	53 (13)
<i>Prostate cancer</i>	56 (13)
<i>Other</i>	146 (35)
<i>Unknown</i>	35 (8)
Time since diagnosis	
<i>0-3 months</i>	44 (11)
<i>4-6 months</i>	82 (20)
<i>7-12 months</i>	79 (19)
<i>1-2 years</i>	66 (16)
<i>More than 2 years</i>	141 (34)
Stage of cancer at diagnosis	
<i>Early</i>	208 (51)
<i>Advanced and/or incurable</i>	135 (33)
<i>Don't know</i>	62 (15)
Treatments received	
<i>Have received surgery only</i>	12 (2.8)
<i>Have received chemotherapy only</i>	29 (6.9)
<i>Have received radiation therapy (radiotherapy) only</i>	44 (10)
<i>Have received other treatment only</i>	12 (2.4)
<i>Have received no treatment</i>	8 (1.9)
<i>Have received more than one cancer treatment</i>	318 (75)

^a not all columns sum to 423 due to missing data

Table 2 – Level of agreement between preferred and perceived involvement in last important treatment decision

Perceived involvement, n=416 (%)	Preferred involvement, n=416 (%)					Total
	Patient only	Mainly patient	Collaborative	Mainly doctor	Only doctor	
Patient only	10 (2.4)	9 (2.2)	3 (0.7)	0	0	22 (5.3)
Mainly patient	5 (1.2)	77 (19)	10 (2.4)	1 (0.2)	1 (0.2)	94 (23)
Collaborative	1 (0.2)	22 (5.3)	118 (28)	6 (1.4)	1 (0.2)	148 (36)
Mainly doctor	0	3 (0.7)	20 (4.8)	24 (5.8)	5 (1.2)	52 (13)
Only doctor	0	4 (1)	11 (2.6)	26 (6.3)	59 (14)	100 (24)
Total	16 (3.9)	115 (28)	162 (39)	57 (14)	66 (16)	416 (100)

Table 3 – Characteristics of study participants who indicated whether they were asked by their healthcare provider about their preference for involvement in treatment decision making

Characteristics	Respondents n= 365 (%) ^a			P value ^b
	Asked	Not asked	Not applicable	
<i>Gender</i>				
Male	89 (44)	35 (43)	32 (39)	0.57
Female	113 (56)	46 (57)	50 (61)	
<i>Age group</i>				
49 years or younger	29 (15)	9 (11)	12 (15)	0.60
50-59 years	43 (22)	27 (34)	15 (18)	
60-69 years	67 (34)	25 (31)	31 (38)	
70 years or older	57 (29)	19 (24)	24 (29)	
<i>Cancer type</i>				
Breast	67 (44)	29 (48)	21 (40)	0.64
Colon	25 (16)	12 (20)	10 (19)	
Prostate	29 (19)	7 (12)	9 (17)	
Other	33 (21)	12 (20)	12 (23)	
<i>Time since diagnosis</i>				
0-3 months	21 (11)	13 (16)	7 (8.5)	0.72
4-6 months	43 (22)	14 (17)	14 (17)	
7-12 months	38 (19)	13 (16)	17 (21)	

<i>1-2 years</i>	29 (15)	13 (16)	14 (17)	
<i>More than 2 years</i>	65 (33)	28 (35)	30 (37)	
<i>Stage of cancer at diagnosis</i>				
<i>Early</i>	100 (52)	34 (43)	40 (49)	0.23
<i>Advanced and/or incurable</i>	68 (35)	31 (39)	25 (31)	
<i>Don't know</i>	25 (13)	15 (19)	16 (20)	

^a not all columns sum to 365 due to missing data

^b Chi-square test

Table 4 – Characteristics associated with discordance between preferred and perceived involvement in decision making (logistic regression)

	Unadjusted odds for experiencing discordance between preferred and perceived involvement			Adjusted odds for experiencing discordance between preferred and perceived involvement		
	Odds ratio	95% CI	P value	Odds ratio	95% CI	P value
<i>Being asked</i>						
<i>Yes</i>	<i>Referent</i>			<i>Referent</i>		
<i>No but wanted this</i>	2.17	0.99 – 4.75	0.05	2.37	1.07 – 5.20	0.03
<i>No but did not want this</i>	0.76	0.37 – 1.56	0.46	0.85	0.41 – 1.76	0.67
<i>Age (in years)</i>	1.00	0.98 – 1.02	0.46	1.00	0.97 – 1.02	0.91
<i>Gender</i>						
<i>Male</i>	<i>Referent</i>			<i>Referent</i>		
<i>Female</i>	0.88	0.58 – 1.34	0.56	1.03	0.59 – 1.8	0.90

Table 5 – Level of agreement between preferred and perceived involvement in last important treatment decision for the reduced sample included in regression analyses

Perceived involvement, n=280 (%)	Preferred involvement, n=280 (%)					Total
	<i>Patient only</i>	<i>Mainly patient</i>	<i>Collaborative</i>	<i>Mainly doctor</i>	<i>Only doctor</i>	
<i>Patient only</i>	9 (3.2)	6 (2.1)	2 (0.7)	0	0	17 (6)
<i>Mainly patient</i>	5 (1.8)	58 (21)	8 (2.8)	1 (0.3)	1 (0.3)	73 (26)
<i>Collaborative</i>	1 (0.3)	14 (5)	83 (30)	4 (1.4)	1 (0.3)	103 (37)
<i>Mainly doctor</i>	0	0 (0)	14 (5)	18 (6.4)	2 (0.7)	34 (12)
<i>Only doctor</i>	0	1 (0.3)	7 (2.5)	16 (5.7)	29 (10.3)	53 (19)
Total	15 (5.3)	79 (28)	114 (41)	39 (14)	33 (12)	280 (100)